#### INDIANA FIRST STEPS PROGRAM

#### BEST PRACTICES IN EARLY INTERVENTION

## INTRODUCTION

### **IDEA Part C, Early Intervention Services**

In November of 1975, the United States Congress passed Public Law 94-142, known as the Education for All Handicapped Children's Act (EHA). This legislation defined the education rights of children and adults with disabilities. Public Law 99-457 amended the EHA in 1986. It established a discretionary program (Part H) for states to provide Early Intervention Services for infants and toddlers (from birth to thirty-six months) and their families. In 1990, the law was again amended and the name was changed to the Individuals with Disabilities Education Act (IDEA). IDEA was further amended in 1991 to Public Law 102-119. It was this amendment that required transition plans from Early Intervention services to Part B (public special education preschool) programs. Public Law 105-17 reauthorized IDEA in 1997. In this reauthorization, Part H became Part C.

More importantly, the 1997 reauthorization of IDEA reemphasized the requirement that states ensure that Part C services for eligible infants and toddlers be provided in natural environments. For many this meant shifting services from segregated, clinic-based programs (therapy clinics, hospital departments, developmental centers) to environments such as children's homes, childcare centers and preschools. This requirement, however, has not only meant a shift in *where* services are provided, but also a change in *how* services are provided.<sup>1</sup>

In the last ten years, Indiana First Steps has evolved from a centered-based, infant/toddler classroom model to one that now provides most services in the child's home or childcare setting. Clearly, First Steps services have shifted the" where" services are provided, but continues to struggle with the "how" services are provided. Often, direct therapy services continue in a traditional medical model of care with emphasis on treating or fixing the underlying medical condition, using a high intensity and frequency level. Interventions are directed at the child, many times with no caregiver present. This was not the intention of the IDEA legislation. IDEA, Part C is a program for children with or at risk for developmental delay and their families. It was not intended to replace or provide for all therapy services needed by children with medical diagnoses or conditions. The goal of First Steps is to maximize development through direct services and family training, while coordinating all other child services and family resources. To this end, just as Congress reauthorized IDEA, Part C in 1997 with an emphasis on natural environments, Indiana First Steps continues its shift away from a traditional medical based model to one of naturalistic interventions that emphasizes the uniqueness of each child and family, with individualized services developed to meet their specific needs and desired outcomes The measure of our success should be how much the family knows when the child and family are ready to transition out of the Indiana First Steps Program. It is wrong for us to let parents think that "therapy alone" is the reason the child's successful outcomes.

<sup>&</sup>lt;sup>1</sup> Shelden, M.I. and Rush, D. The Ten Myths about Providing Early Intervention Services in Natural Environments. Inf Young Children, 2001: 14(1): 1-13.

Naturalistic interventions are those strategies that identify and use opportunities for learning that occur throughout the child's natural activities, routines, and interactions; follow the child's lead; and use natural consequences. <sup>2</sup> Services previously directed solely at the child, with specific instructions given to the caregiver, are now focused on supporting the child and the caregivers in their everyday experiences and activities. Most early intervention providers have been trained to *provide*, thus most families *receive* services in a traditional model where therapy is delivered to the child as the family watches, remains in the waiting area, or at best, receives a home program to administer outside of therapy sessions. The goal of early intervention should be to support children in being and doing being with people who they want and need to be with and doing what they want and need to do.3 "The amount of service is not what's important, because all the child's learning occurs between sessions. It is the work the family and other people who work with the child do that makes for progress." <sup>4</sup> These two elements – family and community- are key to the success of early intervention. A family alone, a health worker alone, a therapist alone, a social worker alone is unlikely to achieve the success that might be possible through involvement and coordination of the community.<sup>5</sup>

Indiana First Steps embraces the concept of natural environments, as both a place and a routinebased structure for the provision of early intervention services and supports to eligible children and families. In April of 2000, the Division of Family and Children regarding Natural Environments issued a policy statement. "The implementation of policy related to Natural Environment must focus on helping infants and toddlers achieve appropriate developmental outcomes." When early intervention cannot be achieved satisfactorily for an infant and toddler in a natural environment, federal law does allow the IFSP team to decide on an individual basis, that services may be provided in a setting other than the natural environment. The Indiana First Steps system also allows the IFSP team, (on which parents are participating members), to make the decisions regarding the provision of early intervention services. As written in the Bureau of Child Development - Natural Environments Policy Statement of April 2000, "Only when a team cannot effectively provide services within the child's routines is discussion to occur regarding the provision of services in another setting. Personal preferences and/or convenience for providers or family are not acceptable justification. Justification must discuss how efforts to provide services in the natural environment were conducted and why these have been determined by the team to be unsuccessful. The justification must include a plan for how services will be generalized into the child's daily routines and activities." A December 2000 completion date for all IFSP reviews for compliance with Natural Environments was set. Indiana further clarified its support of natural environments in its 2001 publication, Early Intervention in Everyday Routines, Activities, and Places: Guidelines For Indiana.

This Best Practice document reinforces Indiana's natural environment philosophy that promotes early intervention in everyday routines, activities and places. This philosophy provides the framework for all services and supports offered by the Indiana First Steps System. As such, Indiana has no need for discipline, intervention or modality specific Best Practice guidelines. The Best Practice Guidelines included in this manual apply equally to all early intervention services, supports and professional disciplines.

<sup>&</sup>lt;sup>2</sup> McWilliams, RA. How to Provide Integrated Therapy. In: McWilliams RA, ed. Rethinking Pull-out Services in Early Interventions. Baltimore: Paul H. Brookes; 1996:49-69.

<sup>&</sup>lt;sup>3</sup> Shelden, M.I. and Rush, D. The Ten Myths about Providing Early Intervention Services in Natural Environments. Inf Young Children, 2001: 14(1): 1-13.

McWilliams, RA. It's Only Natural - To Have Early Intervention in the Environments Where It's Needed. Young Exceptional Children Monograph Series No. 2. 17-25.

<sup>5</sup> Blackman 14 Early lets 3.

Blackman, JA. Early Intervention: A Global Perspective. Inf Young Children 2002; 15(2): 11-19.

#### EARLY INTERVENTION OVERVIEW

# Why is Early Intervention Important?

Research from an array of both longitudinal and cross-sectional studies of children from birth to age six years with a variety of disabilities, documents the educational and economic benefits of early intervention for infants and young children at risk.<sup>6</sup> These benefits were summarized in the House Report accompanying PL 99-157.

- 1. Intelligence is enhanced in some children.
- 2. Substantial gains are made in all areas of development, including physical, cognitive, language and speech, psychosocial, and self-care development.
- 3. Secondary disabling conditions are inhibited or prevented.
- 4. Family stress is reduced.
- 5. Dependency and institutionalization are reduced.
- 6. The need for special education services at school age is reduced.
- 7. The nation and society are spared substantial health care and education costs.

# What Should Early Intervention Look Like?

Early intervention services should be designed to meet the individualized developmental needs of the infant/toddler and family. As each child and family is different, each early intervention program is different. McWilliam and Strain (1993) identified the following five indicators of quality services:

- 1. Services should be delivered in the least restrictive and most natural environment.
- 2. Services should be family-centered and responsive to family priorities.
- 3. Service delivery should be trans-disciplinary.
- 4. Service delivery should be guided by empirical results and family and professional values.
- 5. Services should be individualized to the child/family and developmentally appropriate.<sup>8</sup>

Early intervention service to infants and toddlers should be guided by some basic assumptions about young children as learners. First, young children are active learners. Through mental and physical activity, even very young children are working at making sense of their environments. Second, young children can learn as a result of planned interventions. They learn through repeated experiences with people and materials. Third, young children learn through social interactions with adults and with other children. They learn best when their caregivers and other providers are responsive to their interests, preferences, abilities, characteristics, and health. Fourth, effective intervention strategies are those that promote learning and development.

<sup>9</sup> Widerstrom, et al p.262

<sup>&</sup>lt;sup>6</sup> Wilderstrom, A. Mowder, B. & Sandall, S. (1997) <u>Infant Development and Risk - An Introduction.</u> Paul H. Brookes Publishing Co. Baltimore, p. 3-4.

<sup>&</sup>lt;sup>7</sup> Smith, B.J. (1989). Early Intervention public policy: Past, present and future. In J.B. Jordan, J. Gallagher, P.L. Hutinger, & M.B. Karnes (Eds.) *Early Childhood special education: Birth to three* (pp. 213-229). Reston, VA: Council for Exceptional Children.

<sup>&</sup>lt;sup>8</sup> McWilliam, R.A., & Strain, P.S. (1993). Service delivery models. In DEC Task Force on Recommended Practices (Ed.) *DEC recommended practices: Indicators of quality in programs for infants and young children with special needs and their families* (pp. 40-46). Reston, VA: Council for Exceptional Children.

Individualization in intervention tailors the early intervention program and services to be developmentally appropriate for the child and recognizes meaningful individual and family differences.

#### What Services Are Available?

The following services are available through the Indiana First Steps program for eligible children/families:

- Assistive technology devices include a variety of items, equipment, materials or services, used with individual children to increase, maintain or improve their functional capabilities. May also include adaptations to toys and learning materials that permit the child to be more successful in their play and developmental activities; evaluation and adaptation of currently used equipment; or evaluation and adaptation of the child's environment.
- Audiological services can identify if the child has a hearing loss, how significant the loss is and what it means to the child's ability to communicate and develop. May include training in specific ways of communication, fitting with and maintenance of hearing aids and insuring that the family can operate and care for the hearing aids.
- Family training, counseling and home visits are provided to assist the family in understanding the special needs of the child and enhancing the child's development. Early intervention providers credentialed at the specialist level may provide these services.
- **Health services** refer to medical care provided during the time a child is receiving other early intervention services, so that the child will benefit from the other early intervention services. These may include intermittent catheterization or tracheostomy care. It may also include helping the child's physician work with other early intervention providers concerning the special health needs of the child.
- **Medical services for diagnostic purposes** are only for diagnostic/evaluation purposes to determine a child's developmental status and need for early intervention services, when eligibility cannot otherwise be determined.
- **Nursing services** are individual interventions conducted with the child and/or family that support the other early intervention services. They may include assessment of health status, provision of care to prevent health problems, restore or improve functioning, and promote optimal health and development.
- **Nutrition services** focus on specific nutritional needs, including assessment and development of a nutrition plan that is individualized and referral to appropriate community resources.
- Occupational therapy services develop adaptive and self-help skills with focus on developing skills related to sensory-motor integration, coordination of movement, fine motor skills, self-help skills (including feeding), and may include adaptive devices or equipment to help the child in these activities.
- **Physical therapy services** focus on gross motor skills and the ability to move and effectively use his/her arms, legs, trunk and head.
- **Psychological services** are concerned with the child's learning and social/emotional development. Included is administration of psychological/developmental assessments, planning and managing a program of psychological services that may include counseling the child and family, and providing parent training and education programs specific to the child's developmental needs.
- Service coordination ensures that the family is well informed of their rights, opportunities and responsibilities within the program. They assist the family in assuming an advocacy role for their child and they assist the family to develop, monitor and revise the Individual

Family Service Plan (IFSP) to include appropriate outcomes and services that are family centered and supportive of the family's lifestyle and schedule. Service Coordinators work with the family to identify and plan for transitions within and out of First Steps.

- Social work services support the family by assisting them to resolve difficulties or concerns that interfere with or prevent the child from participating fully in early intervention services. Service may include family counseling and linking the family with resources or other services in their community.
- **Special instruction** (Developmental Therapy/Early Childhood Education) focuses on infant/toddler development and ways to promote development. This includes designing learning environments and activities to promote development across all domains: cognitive; physical; communication; social/emotional; and adaptive.
- Speech-Language Pathology (SLP) services focus on receptive (understanding what is said) and expressive (being able to speak so that others can understand) communication. It may include the use of sign language, augmentative communication devices or other assistive technology. SLP may also be involved with the child's feeding program.
- **Transportation and related costs** include travel costs that families must bear so that their child can participate in early intervention evaluation and/or services.
- **Vision services** includes evaluation and assessment of the child's ability to see and orientation/mobility services to enhance the vision-impaired child's ability to move about safely.
- Other services are individualized services or supplies not covered elsewhere, which have been requested and justified by the IFSP team and receive prior approval from the state.

These services are provided by qualified and licensed/certified personnel. First Steps recognizes the importance of both education and experience in providing services to infants/toddlers and their families to maximize outcomes. Some services have an associate and specialist level of providers. Qualifications and experience requirements are outlined in the *Early Intervention Personnel Guide* 2002. (Additionally, Service Coordinators and Developmental Therapists/Early Childhood Specialists without one year documented experience with infants/toddlers are required to be supervised for one year by a credentialed specialist.) All services are provided in conformity with an Individualized Family Service Plan (IFSP).

- Audiologist
- Family therapists
- Nurses
- Nutritionists
- Occupational therapist
- Orientation and mobility specialist
- Pediatrician and other physicians
- Physical therapist
- Psychologist
- Service Coordinator
- Social workers
- Developmental Therapists/Early Childhood Specialists
- Speech and language pathologist
- Vision specialist

# Who is Eligible for Indiana First Steps Program?

Only children between birth and thirty-six months of age and in need of early intervention services are eligible for First Steps services. Indiana has a very broad definition of eligibility, which includes a documented developmental delay; a diagnosed physical or mental condition that is likely to result in a developmental delay or a biological risk factor that is likely to result in a developmental delay. It should be noted here that, it is possible to meet eligibility criteria without needing First Steps services. Services are only provided to support an IFSP outcome. If a child has a medical condition or biological risk factor, but no evidence of developmental delays, then services may not be appropriate. The family would be informed of their rights and the child could be reevaluated in six months, or sooner, if their status changed.

Eligibility must be determined by a multidisciplinary team using multiple sources of information and must be re-determined annually. A multidisciplinary team must include the Intake and/or Service Coordinator, the family, and representatives from at least two early intervention disciplines. The child's primary care provider or a specialty physician may be considered part of this multidisciplinary team if the physician specifically notes the documented delay or other eligibility criteria on the health summary, on the order for evaluation, or in person through attendance at the meeting. Another example of multidisciplinary team participation may include an Eligibility Determination Team (ED Team) evaluation. In an ED Team evaluation, different disciplines evaluate the child and interview the family at the same time. One team member may provide hands on manipulation/interaction with the child/family, while the other team members observe and record findings pertinent to their discipline. Each arena team member is responsible for writing a discipline specific section of the evaluation report with discipline specific recommendations, if warranted.

In Indiana, eligibility may be determined using informed clinical opinion when standardized assessment instruments are not appropriate or are not available for that discipline. Informed clinical opinion should be justified with direct observation data and rationale to support the need for services. If existing information from medical records is adequate to determine eligibility, no additional assessments may be necessary. The categories of eligibility are defined below.

#### **Developmental Delay**

Children shall be considered eligible to receive early intervention services if they are experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures. When using standardized assessments or criterion-referenced measures to determine eligibility, a developmental delay is defined as: (1) delay in one or more areas of development as determined by: (A) one and one-half (1 1/2) standard deviations below the mean; or (B) twenty percent (20%) or more in function below the chronological age (adjusted for prematurity, if applicable) on an assessment instrument that yields scores in months; or (2) delays in two (2) or more areas of development as determined by: (A) one (1) standard deviation below the mean; or (B) fifteen percent (15%) or more in function below the chronological age (adjusted for prematurity, if applicable) on an assessment instrument that yields scores in months (Rule 7. Eligibility 470IAC3.1-7-1). The five developmental domains include: cognitive, physical, communication, social/emotional and adaptive.

In calculating the developmental delay, the age of a premature infant should be adjusted to account for the prematurity of the infant, usually through the first two years of life. For example, a child born at 30 weeks gestation, would have his/her chronological age adjusted down 10 weeks. When he/she is chronologically five months (20 weeks) old, their adjusted age would be 2 ½ months (10 weeks) old. They would be expected to perform at the 2 ½ month level and not at a 5 month level.

Ideally, developmental delay should be determined through the use of appropriate standardized or norm referenced instruments. When standardized tools are not available or not appropriate, informed clinical opinion may be used. When developmental delay is determined by informed clinical opinion of the early intervention team (including the parents), it should be supported by:

- a complete developmental history, as currently reported by the parent or primary caregiver;
- a review of pertinent records related to the child's current health status and medical history;
- consideration given for functional status, rate of change and prognosis for change in the near future based on anticipated medical or health factors;
- at least one other assessment procedure to document delayed development, such as observational assessment or planned observation of the child's behaviors and parent child interaction or documentation of delayed development by use of non-standardized assessment devices, such as developmental checklists. (IAC 3.1-7-1)

#### High Probability of Development Delay - Diagnosed Physical or Mental Condition

In order to be eligible in this category the child must have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay. Specific diagnoses and conditions of eligibility are defined in Indiana law. These diagnoses and conditions must be supported by a physician or psychologist indicating what the physical or mental condition is and a multidisciplinary evaluation report that Early Intervention services are needed. The categories include:

Chromosomal abnormalities/genetic disorder;

- Neurological disorder;
- Congenital disorder;
- Sensory impairment including vision and hearing;
- Severe toxic exposure;
- Severe infectious disease; and
- Atypical development disorder.

#### At Risk of a Developmental Delay

The eligibility definitions include a final category defined as Biologically At-Risk. Children, from birth to thirty-six months of age, shall be considered eligible to receive early intervention services if they are at risk of having substantial developmental delays, due to known biological factors, if early intervention services are not provided. To be considered at risk of developmental delay, the following must be present: 1) one or more biological factors is present; 2) a physician statement or report indicating the condition that is likely to lead to developmental delay; and 3) a multidisciplinary evaluation report that Early Intervention services are necessary to meet the needs of the child. Biological at risk factors include:

- Limited prenatal care;
- Maternal prenatal substance abuse;
- Severe prenatal complications;
- Severe perinatal complications;
- Asphyxia;
- Very low birth weight;
- Small for gestational age; or
- Severe postnatal complications.

Eligibility must be clearly documented. Each child must be identified as having either a documented developmental delay, or a medical diagnosis/condition that has a high probability of resulting in developmental delay or a biological at-risk factor having the likelihood of substantial developmental delay. Indiana uses a common Eligibility Determination Form. For more detail regarding the eligibility definition and the Eligibility Determination Form, refer to the First Steps Practice Manual. Eligibility determination will result in one of the three findings below:

- Child is eligible and in need of services, proceed to development of an IFSP.
- Child is eligible, but not in need of services. The family will receive information on their rights, child's current developmental level, community supports/services, and how to contact the system should they have further concerns or the child's status changes.
- Child is not eligible. The family receives information on their rights, the child's current developmental level, community supports/services, and how to contact the system should they have further concerns or the child's status changes.

#### **How Are Services Provided?**

A major requirement and a guiding feature of early intervention services is the Individualized Family Service Plan (IFSP). The IFSP includes specific expected outcomes and serves as the plan of action for achieving those outcomes. IFSP development involves the family and early intervention professionals working together to develop a plan that describes the services and supports that will enhance the development of the child and the capacity of the family to meet the special needs of the child (Federal Register, 1989). The law and regulations that provide guidance for developing the IFSP recognize the family as the central focus of early intervention policies and practices. That is, families are the context within which early intervention efforts take place.<sup>10</sup>

In order to develop a meaningful and useful IFSP, the process must be one that encourages and respects families, responds to their priorities and concerns, and builds on their strengths. It is a cooperative effort. Team members provide information from observations and assessments. Parents and family members contribute important information based on their intimate knowledge of the child, their concerns for the child and a discussion of the child and family routines. Sharing information about the child's and the family's strengths and needs leads to the development of meaningful goals and outcomes. Evaluation of the IFSP will be measured in relation to the child's level of functioning, thus it is important that this be described as accurately as possible. The IFSP must be written and implemented within 45 days of referral. It must be reviewed in six months. Eligibility must be redetermined annually.

Outcomes are positive statements of the changes that the family and team members want to see for the child and the family. Written in easy to understand terms, outcomes should specify what is to occur as a result of planned actions. As outcomes are written, resources, strategies and actions that will be useful in meeting the outcomes are also discussed and written into the IFSP. The IFSP lists each of the early intervention services that are necessary to meet the needs and concerns of the child and family. This includes stating the frequency and duration of each service in the plan, who will provide that service, and where the service will be provided. The final piece of the IFSP is the plan for transition. Transitions may occur as the child's level of function or needs change. Transition includes movement into, through and out of the First Steps Program.

<sup>&</sup>lt;sup>10</sup> Sandall page 237

# What is Family Centered Care?

The Indiana First Steps System is based on family centered, coordinated services. A family centered approach to intervention is emphasized in Part C of IDEA. Part C mandates family involvement in a variety of ways. Families are to be involved in: 1) establishing outcomes for their child within the context of the family system; 2) designing and implementing strategies for intervention; and 3) determining the progress that their child is making. Critical elements of early intervention are communication between the family and the service providers and respect for the ability of each family to make informed decisions about their child.

Part C provides a structure for family involvement via the Individualized Family Service Plan (IFSP). The IFSP is based on the resources, concerns and priorities of each family and results in the realization of outcomes for the family and child. Another way to ensure family involvement is the Service Coordinator. The Service Coordinator assists the family in obtaining and coordinating appropriate services and resources for their child and family.

In that a baby/toddler is totally dependent on others for all of his/her needs, service providers should always consider the family context when assessing or treating a child. The environment must include the relationship between the infant/toddler and his/her caregivers. Caregivers provide the necessary safety, comfort, nourishment and stimulation that enable an infant to develop. Observing, understanding and supporting this fundamental foundation for young children is essential in determining the child's ability to adapt to and function in his/her environment. By observing an infant/child in the context of his/her environment, one more fully understands the developmental and maturation processes of an infant.

The Division for Early Childhood (DEC) has made the following statement; "Family-based practices provide or mediate the provision of resources and supports necessary for families to have the time, energy, knowledge, and skills to provide their children learning opportunities and experiences that promote child development. Resources and supports provided as part of early intervention/early childhood special education are done in a family-centered manner so family-based practices will have child, parent, and family strengthening and competency-enhancing consequences." This is a significant change in approach to treatment philosophy for many providers who were used to the more traditional medical model of child-focused services. The philosophy of family-centered care supports a collaborative relationship between families and professionals. The goal of this relationship is to be responsive to the priorities and concerns of the family while making use of all available resources.

Indiana has defined key elements of family-centered services in its Vision Statement. "Our goal is to serve infants and toddlers with or at-risk for special developmental needs by providing a family-centered, comprehensive, coordinated, neighborhood-based system of services for them and their families. To this end we:

- ➤ Involve families in the development, implementation and evaluation of the service system.
- Make services accessible and widely dispersed throughout the community.
- ➤ Offer choices to families that are typical of the choices available to all families of young children in their everyday routines, settings, and activities.
- ➤ Offer services that are culturally sensitive and tailored to individual needs of the child as well as family priorities.

- ➤ Offer services that exemplify best practices in early intervention and be accountable for the quality of these services by evaluating them in terms of process and outcome.
- Respect families by acknowledging that they are the primary constant in the child's life and by helping them to make choices as well as supporting them as they implement those choices, even when we disagree with them.
- Focus on prevention of, as well as intervention for, disabilities among infants and toddlers, keeping in mind that the ultimate goal is maximizing the potential of children so that they can function as contributing members of society as adults.
- Creatively use existing resources and seek additional resources to maximize service options for families and to fairly compensate staff providing services.

#### What Are Natural Environments?

Natural environments have been defined as those settings that are natural or normal for the child's age peers who have no disabilities. Natural environment is more than a physical setting. It is the methods and approaches used to provide early intervention services that support the daily routines of family life. In the 2001 publication, *Early Intervention in Everyday Routines, Activities, and Places: Guidelines for Indiana*, the Indiana First Steps System defines natural environment as "everyday routines, activities, and places."

Natural environments are services and supports that occur in settings most natural and comfortable for the child and family. They should foster opportunities for the development of peer relationships with children without disabilities. Home-based interventions and inclusive community settings are preferred. The unique routines of each child/family should be the underlying construct for all services and interventions. Additionally, the characteristics of the family's community, and the development of a natural system of supports within the community should be promoted at all times.

# Why is Natural Environment so Important?

The Indiana First Steps System has made a concerted effort to advance the provision of early intervention services in a child's natural environments. This is in response not only to federal law, but also in response to current goals and beliefs in the early intervention field. Federal law requires that "To the maximum extent appropriate to the needs of the child, early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate."

The Governor's Interagency Coordinating Council on Infants and Toddlers (ICC) adopted the following position statement in 2000 on natural environments for Indiana's families and providers: "It is the belief and recommendation of the Governor's Interagency Coordinating Council on Infants and Toddlers that services and supports are most effective when they are provided within the context of families' everyday routines, activities and places...While where and when services are provided are essential elements in providing quality services in the natural environments, equally important are the elements of which services and how those services are delivered. Natural Environment refers not only to the place where services occur, but also to the natural schedule of activities for the child/family and

how services can be planned so that the child will be able to successfully participate in the family routine and the community at large. Therefore, services provided in these everyday routines, activities and places must be developmentally appropriate and relevant to families' lives."

Early Intervention research has demonstrated that children learn best when they have the opportunity to learn and practice skills in the context of everyday routines, activities and places. The benefits of providing services in natural environments can be summarized in these statements:

- A child is more likely to generalize skills learned in natural environments.
- All children learn to understand and accept differences.
- A child is more likely to learn appropriate and effective social skills.
- Every child has an opportunity to participate in his or her community.
- Communities recognize that children with special needs are children first.
- Children and families experience a sense of belonging.
- Children are more likely to remain in the home and not require residential placement.

Federal law does allow the IFSP team to decide on an individual basis when early intervention services may be provided in a setting other than the natural environment, only if early intervention cannot be achieved satisfactorily for an infant and toddler in a natural environment. The Indiana First Steps system allows the IFSP team to make the decision regarding service delivery. "Only when a team cannot effectively provide services within the child's routines is discussion to occur regarding the provision of services in another setting. Personal preferences and/or convenience for providers or family are not acceptable justification...Justification must discuss how efforts to provide services in the natural environment were conducted and why these have been determined by the team to be unsuccessful. The justification must include a plan for how services will be generalized into the child's daily routines and activities..." (BCD Natural Environments Policy Statement April 2000)

#### What is Best Practice?

Best Practice is the term used to describe current, evidence-based practice. Services and supports should reflect the current research for best practice accepted in the field of early intervention in order to yield the most positive outcomes. Service providers and families should work in teams, sharing their knowledge and skills, communicating, planning and collaborating with each other. The measure of a provider's success is how much the family knows when the child and family transition. It is wrong for providers to let parents think that "therapy alone" is the reason the child developed or achieved outcomes.

Plans should be outcome oriented and understandable to families. *They should be based on developmentally appropriate practices geared to the individual needs of the child/family.* Transitions should be well planned and collaborative in nature. As knowledge about early intervention and child development is always increasing, service and supports should always be based on the most accurate and recent research available, but not on modalities that are untested or not found to be age-appropriate for infants and toddlers. Providers have a responsibility to keep current on early childhood development, research and interventions through continuing educations, professional journals and academic coursework.

The National Association for the Education of Young Children has established principles of child development and learning that indicate developmentally appropriate practice. These principals are applicable to all service areas and professionals who are working with young children regardless of the

child's age, behavior, impairment or disability, and must serve as the basis for all early intervention services. The principles are:

- 1. Domains of children's development (physical, social, emotional, and cognitive) are closely related. Development in one domain influences and is influenced by development in other domains.
- 2. Development occurs in a relatively orderly sequence, with later abilities, skills, and knowledge building on those already acquired.
- 3. Development proceeds at varying rates from child to child as well as unevenly within different areas of each child's functioning.
- 4. Early experiences have both cumulative and delayed effects on individual children's development; optimal periods exist for certain types of development and learning.
- 5. Development proceeds in predictable directions toward greater complexity, organization, and internalization.
- 6. Development and learning occur in and are influenced by multiple social and cultural contexts.
- 7. Children are active learners, drawing on direct physical and social experience as well as culturally transmitted knowledge to construct their own understandings of the world around them.
- 8. Development and learning result from interaction of biological maturation and the environment, which includes both the physical and social worlds that children live in.
- 9. Play is an important vehicle for children's social, emotional, and cognitive development, as well as a reflection of their development.
- 10. Development advances when children have opportunities to practice newly acquired skills as well as when they experience a challenge just beyond the level of their present mastery.
- 11. Children demonstrate different modes of knowing and learning and different ways of representing what they know.
- 12. Children develop and learn best in the context of a community where they are safe and valued, their physical needs are met, and they feel psychologically secure.

# Why is Defining Best Practice Important?

The Governor's Interagency Coordinating Council on Infants and Toddlers (ICC) Vision Statement for the First Steps Early Intervention System states, "...offer services that exemplify best practices in early intervention and remain accountable for the quality of these services by evaluating them in terms of process and outcome." This Vision Statement is a tool to help ensure that infants and children with or at risk for developmental delay receive early intervention services that are grounded in scientific research on effective practices to maximize child/family achievement of IFSP outcomes.

The Indiana First Steps System is developing Best Practice Guidelines to help families and providers make informed decisions and choices about services. The Guidelines are a tool for parents and providers to utilize in tailoring a program to meet the needs of the individual child and family. The guidelines should not be interpreted as a standard of practice. The responsibility remains with the provider and the IFSP team to use their expertise to develop an IFSP that is appropriate to the unique needs and circumstances of each child/family.

A guideline can only be as good as the evidence on which it is based. The First Steps system does recognize that at the present time there is limited quantitative research validating clinical efficacy of intervention strategies for early intervention in the literature. As evidence-based practice is gaining attention across the spectrum of healthcare and education, this is anticipated to change. As new evidence is identified, the recommendations and position statements may no longer be appropriate.

Therefore, revision to the guidelines will be necessary to ensure that the guideline is based on the best current evidence

# **How Are the Best Practice Guidelines Developed?**

The Indiana First Steps Best Practice Guidelines are developed from a comprehensive review of:

- Professional associations, journals and publications;
- Federal and state law;
- Federal and state regulatory manuals;
- Healthcare accreditation manuals; and
- Current literature.

There is a great deal of information on treatment options or philosophies of intervention for children who are not developing as anticipated. In the process of developing the Best Practice guidelines many treatment options/philosophies were reviewed in detail. Special attention was given to scientific evidence within the literature. The Indiana First Steps System supports only those interventions/philosophies found to have scientific evidence to support their efficacy, are age appropriate to infants and toddlers and have the ability to support family-centered care in the child's natural environment. There are a number of therapies in current practice that do not have credible scientific research documenting their effectiveness or have no evidence to support their use for infants and toddlers. Further, when embracing a philosophy of naturalistic interventions emphasis is placed on the child/family's routines, activities and places and not on prescribed interventions that are not routine for the child/family.

# **Can Interventions Not Defined in Best Practice Be Utilized?**

In Indiana, families have the right to an appeal and due process. An appeal may be made to the Bureau of Child Development to request consideration for alternative services or service delivery. These requests will be reviewed, taking into account:

- The child and family needs;
- Previously tried intervention or service delivery models;
- The current Best Practice Guidelines and current literature; and
- Any new information the family or providers supply.

The Indiana First Steps System supports services, within the scope of IDEA Part C, that are written into the IFSP and which are considered to be provided in the natural environment. Only when an IFSP team determines that it cannot effectively provide services within the child's routines to meet the IFSP outcomes, is discussion to occur regarding the provision of services in another setting. Personal preferences and/or convenience for providers or family, are not acceptable justification. Justification must discuss how efforts to provide services in the natural environment were conducted and why these have been determined by the team to be unsuccessful. The justification must include a plan for how services will be generalized into the child's daily routines and activities.

There are significant concerns regarding the use of interventions or treatment lacking scientific evidence. Among these are interventions that:

• offer false expectations or hopes to the family in the outcomes of an intervention;

- have the tendency for all intervention efforts to be focused on an approach that addresses a narrow aspect or behavior of the child;
- have not been tested or approved for infants and toddlers, under the age of three years; and
- lack documentation of potential side effects or physical or emotional harm resulting from treatment.

Interventions lacking scientific evidence have been described as having the following characteristics:

- Treatments that are based on overly simplified scientific theories;
- Therapies purported to be effective for a variety of conditions;
- Treatments that claim most children will respond dramatically and that some may be cured;
- Treatment supported by a series of case reports or anecdotal data and not carefully designed research studies;
- Treatments initiated with little or no attention to identifying specific treatment objectives or target behaviors; or
- Therapies are said to have no or unremarkable side effects, thus, there is no reason to do controlled studies." (Nickel)

#### **How Will the Best Practice Guidelines Be Utilized?**

The Best Practice Guidelines will be utilized to:

- Help parents make informed decisions about their child's interventions;
- Assist providers in understanding their roles and responsibilities within the system;
- Serve as a guideline for prior authorization request review; and
- Serve as a guideline for prospective record review.

# **Best Practices in Early Intervention**

# Children with or at risk for developmental delay are identified, referred and evaluated in a timely manner.

- 1. Families are made aware of the First Steps Early Intervention Program through local Child Find and Public Awareness initiatives.
- 2. Children/Families are referred to the System Point of Entry. Families may self refer. Health Professionals and Social Service Providers should refer within two working days of identification or suspicion of developmental delay.
- 3. The SPOE will contact the child/family within two working days of the referral.
- 4. Families will be provided their rights (written and verbal) in their native language.
- 5. Families voluntarily choose to participate.
- 6. Time is spent getting to know the child and the family (listening to their story, understanding their routines and activities).
- 7. The child receives a comprehensive assessment of the developmental domains (cognitive, communication, physical, social-emotional, adaptive) by a multidisciplinary eligibility determination team of professionals.
- 8. The developmental assessment findings and eligibility determination are discussed with the family.

#### Eligible children/families move to IFSP within 45 days of referral

- 1. The family is informed of their rights.
- 2. The family voluntarily chooses to continue to IFSP.
- 3. The family participates in the IFSP with members of the eligibility determination team in attendance.
- 4. The child/family story, routines and activities are discussed and used as the structure for outcomes and services.
- 5. The IFSP team discusses a variety of early intervention model options, including transdisciplinary, direct child treatment, family training and support, etc.
- 6. Services are planned to be provided in the child's natural environment.
- 7. Interventions should focus on functional skills and those that must be performed for the child by an adult, should be given priority.
- 8. Transition plans are discussed and developed.
- 9. Other services, outside of early intervention are listed and/or discussed.
- 10. Outcomes are mutually agreed upon.
- 11. The family is assisted in choosing service providers/service coordinator for the IFSP.
- 12. The primary therapist(s) and consultant therapist(s) are identified or are to be determined at a later date.
- 13. Services, frequencies and intensity are determined and are appropriate for the developmental needs of the child/family, child's age and attention span and the outcomes written in the IFSP.
- 14. Specific modalities are not written into the IFSP.
- 15. The family and the child's primary health care provider sign the IFSP.
- 16. Services may begin.

# Services are provided to the child/family as outlined in the IFSP.

- 1. Services are provided in the natural environment using materials found in the environment, as identified in the IFSP.
- 2. Services are developmental in nature and are age appropriate.
- 3. Services are provided so that all service providers and the family work toward common goals, objectives and outcomes.
- 4. The needs of the child/family at the moment take precedent over predetermined curriculum plans.
- 5. Providers frequently should ask themselves, what do families need to know when I am no longer involved in this child's care and plan accordingly.
- 6. Families/care providers are active participants in all therapy sessions.
- 7. There is adequate documentation provided to the family and for the early intervention record regarding the visit.
- 8. The family's questions and concerns are addressed at each visit.
- 9. Ongoing assessments of the child/family are made at each visit.
- 10. Goals, objectives and outcomes are modified as needed, by and among the family and team members.
- 11. When progress is not noted, the IFSP team should consider consultation and/or changes in services and/or providers.
- 12. Changes in frequency and/or services must be discussed and approved by the IFSP team and entered into the electronic record at the SPOE.
- 13. The IFSP is reevaluated as needed and at least every six months.
- 14. Eligibility is re-determined annually, before the end date of the current IFSP.

#### Transition of the child/family

- 1. Transition is discussed and planned for from the initial IFSP.
- 2. Transition may occur with movement from hospital to home, home to foster home, county to county, "graduation" from early intervention prior to age three or transition to the 3-5 public preschool special education programs (Part B), or other community programs.
- 3. Families are informed of their rights.
- 4. All resources for transition are considered, including "Mom's Day Out", private preschools, public preschool special education, Head Start, private therapy and others as may be available in the child's community.
- 5. With parental consent, the Local Education Agency (LEA) is provided information about the child at 18 and 30 months.
- 6. A transition meeting is conducted between 30 and 33 months with parents participating.
- 7. If eligible for the preschool special education program, an IEP is in place at age three years.
- 8. When leaving First Steps families will know something they didn't know before and they should know that they know.
- 9. There is full documentation of the transition process.

# The Early Intervention Record

- 1. The "official" EI Record is maintained at the SPOE.
- 2. The EI Record contains all consents, eligibility forms, IFSPs, change pages, quarterly notes, service coordination logs and other background information.
- 3. Only those persons employed by the SPOE, BCD staff and service providers with written consents may access a child's EI file. Everyone, except SPOE or BCD staff, accessing the record must sign-in.
- 4. The Intake Coordinator/SPOE is responsible for information from referral to initial IFSP.
- 5. The SPOE is responsible for timely computer data entry and document filing.
- 6. The service coordinator is responsible for all information in the EI Record after the initial IFSP through Transition. This includes quarterly reports from all service providers, service coordinator logs, 6<sup>th</sup> month IFSP reviews, annual re-determination of eligibility, consents, and transition documentation

#### **Service Providers**

- 1. All service providers must meet education and experience standards as outlined in the Personnel Standards.
- 2. Providers must meet credential requirements and recredential every year.
- 3. Providers should seek ongoing education regarding child development (typical/atypical), specific discipline interventions and foundations of early intervention annually.
- 4. Providers should remove themselves from any conflict of interest regarding the recommendation of services, intensity or frequency for the children/families they service.
- 5. All service providers should work in unison to achieve the goals, objectives and outcomes listed in the IFSP.
- 6. Service providers should discuss and provide written information on strategies used and progress made with the family at each visit. This information should be legible and provided in a language and reading level appropriate for the family.
- 7. Service providers should bill only for services provided as outlined in the IFSP and as provided to child/family.

#### **Early Intervention Services**

- 1. Early intervention services should be provided in the natural environment and reflect the routines and activities of the child/family. At the initial IFSP team meeting, opportunities for service delivery in the child's natural environment should be identified. Strategies or interventions outside of the natural environment should not be considered before services provided in the child's natural environment have been determined not to be effective. When early intervention cannot be achieved satisfactorily for an infant and toddler in a natural environment, federal law does allow the IFSP team to decide on an individual basis, that services may be provided in a setting other than the natural environment. The Indiana First Steps system also allows the IFSP team, (on which parents are participating members), to make the decisions regarding the provision of early intervention services. As written in the Bureau of Child Development - Natural Environments Policy Statement of April 2000, "Only when a team cannot effectively provide services within the child's routines is discussion to occur regarding the provision of services in another setting. Personal preferences and/or convenience for providers or family are not acceptable justification. Justification must discuss how efforts to provide services in the natural environment were conducted and why these have been determined by the team to be unsuccessful. The justification must include a plan for how services will be generalized into the child's daily routines and activities."
- 2. Only Early Intervention services needed to meet the IFSP outcomes should be written in the IFSP. Duplication of services should be avoided. Consultative services should be considered when additional input is required to determine if the current IFSP strategies/providers are appropriate and/or need reconsideration. The inclusion of more than one provider from the same discipline on a child's IFSP must be requested by the IFSP team with justification and be prior approved by the Bureau of Child Development. Providers listed on the IFSP who cannot provide the level or specific type of service that is necessary to meet the IFSP outcomes, should remove themselves from the IFSP. Specific modalities, outside of the natural routines, activities and places of the child/family are not routinely covered services of the First Steps Program and must be individually determined by the IFSP team and be supported with written documentation of the justification for service delivery outside of the natural environment.
  - a. This includes specifically named modalities such as HIPPO Therapy, Aquatic Therapy, and others that are not provided in the child's natural environment as part of the family's daily routine.
  - b. When a specific modality, individually authorized and justified for a child, has a certification requirement, (such as HIPPO therapy), the provider of the modality may be required to have documentation of all appropriate certification on file at the Provider Enrollment Unit.
  - c. This includes assistive technology not specific to developmental function.
- 3. Frequency or duration of therapy must be appropriate to meet the IFSP outcomes, developmentally appropriate for infants and toddlers, and not be disruptive to family routine.
- 4. All services should be documented, including date, time in and out, outcomes addressed and how and parent signature concurring with all written documentation.
- 5. Children/families meeting their goals, objectives and outcomes should be transitioned from the First Steps Program in a timely manner.

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